2015

Genetic Discrimination Law in the United States: A Socioethical & Legal Analysis of the Genetic Information Nondiscrimination Act (GINA)

Ken Lefebvre

CPPA Center for Public Policy and Administration
UMassAmherst

Genetic Discrimination Law in the United States: A Socioethical & Legal Analysis of the Genetic Information Nondiscrimination Act (GINA)

Ken Lefebvre
April 26, 2015

Center for Public Policy and Administration
Gordon Hall
418 North Pleasant Street
Amherst, MA 01002
(413) 545-3940

Connecting Ideas with Action

www.masspolicy.org

Genetic Discrimination Law in the United States

A Socioethical and Legal Analysis of the Genetic Information Nondiscrimination Act (GINA)

Ken Lefebvre
Spring 2015

This report is intended to fulfill the capstone requirement for a Master's Degree in Public Policy and Administration at the University of Massachusetts Amherst. The content and opinions herein are those of the author and are not representative of the official stances of the Center for Public Policy and Administration, nor the University.

Executive Summary

In the last several years, genetic sequencing technologies have become widely accessible to consumers as prices have fallen at rates faster than the National Institute of Health had initially predicted. With these lower costs more patients now have access to their own genetic information than ever before, thanks to a host of new services.

Though objective in itself, genetic information is often regarded as an a indicator of social and medical outcomes, with some associations substantiated and others largely reflecting social attitudes. Our understanding of genetic markers as forecasters for certain psychological and physiological disorders is still relatively limited, but associations between certain genes and certain outcomes, however scientifically valid, hold the potential to yield disparate treatment through this new facet of human diversity. There is some concern that this growing library of information is portentous to discrimination in employment and insurance coverage based on these genetic differences; for this reason lawmakers have attempted to alleviate fears of such socially deterministic practices. The Genetic Indiscrimination Act of 2008 (GINA) amends much of these privacy concerns through a series of far-reaching legal protections, however lacunae remain both in the law's language and in the inherent traceability of genetic information itself.

In this report the author will attempt to address why GINA and its counterparts came into being, what kinds of protections they offer, and where they might be improved to benefit the individuals they were written to protect. Some states have attempted to expand on Federal law to address life, longterm care, and disability insurance, however the absence of a current authoritative source on the statutes of all 50 states may hinder the ability of patients to utilize these additional protections. The author also found that some privacy risks may exist in the public disclosure of genomes by a patient's relatives, as genetic technology may allow this information to be used to identify themselves and others whose genomes are listed anonymously in medical databases. Since an individual's genetic information may reveal traits present in other family members, this paper also discusses current GINA/HIPAA disclosure policies, and their shortcomings in providing the genomic information of one patient to others who may medically benefit from this knowledge.

This report concludes that there are some immediate steps that lawmakers and medical professionals could take to better protect individuals from discriminatory practices– largely through education and the expansion of Federal law to cover other forms of insurance. Several other issues addressed here may not be resolved through immediate changes in policy, but may end up being reconciled in court in the ensuing years. In addressing these issues, this paper attempts to evince how discourse among policymakers, scientists, and ethicists has influenced genetic disclosure policy, what this means for current law, and how this may affect future legal outcomes.

Contents

Introduction

The human genome was first decoded in its entirety more than a decade ago, and since that time the availability of whole genome sequencing (WGS) has increased dramatically. Indeed a service that once cost the U.S. government a 2.7 billion dollar investment over ten years, is now available to patients for thousands of dollars in a matter weeks. However with this technology have come a host of concerns over how a growing body of genetic information should be handled, and who should have the right to access this data. Several laws have been passed in an effort to prevent this information from being used in discriminatory practices, however in these early stages of implementation, relatively little is known about their effectiveness and where they could be improved.

This report will analyze how legal and ethical precepts have interacted with the inherent qualitative nature of genetic information, to better understand what current policies are most salient and where such protections have otherwise fallen short. This paper will address the following questions- (1) Why is the legal protection of genetic information increasingly relevant in society today? (2) How has a historical legacy of eugenics informed these protections? (3) What is genetic discrimination and what entitlements are extended to patients by the Federal "Genetic Information Nondiscrimination Act of 2008"? And (4) how might this law and its related counterparts be improved upon in the future? Through these questions this report attempts to evince some of the unresolved challenges genetic services will pose to policymakers in the years ahead.

Background

After more than a decade's work, the Human Genome Project released the first fully-sequenced human genome in 2001; it was a groundbreaking accomplishment for science and society alike, representing the dedication of thousands of researchers and funding in excess of 2.7 billion dollars ("The Human Genome Project Completion", 2010). Symbolically this was the first time that mankind could consider the very building blocks that make up every human being, and though the first sequences represented but a handful of individuals, their unveiling opened a proverbial Pandora's box of medical ethics. Human beings are, on average, 99.5% genetically similar, a smaller margin than geneticists had initially anticipated prior to the Human Genome Project (Wade 2007). Though half a percent may seem insignificant at its face, this proportion of genetic difference still represents roughly 150 million base pairs of codons[1] out of the 3 billion which make up an individual's genetic code. It is these base pair differences that comprise the sum of all human diagnostic genomics.

[1] The nucleobase letters A, T, C, & G which comprise deoxyribonucleic acid or “DNA”.

The Growing Role of Genetic Services

The importance of genetic law has grown significantly in the lives of everyday citizens as the cost for each genomic transcription has dropped at a pace surpassing even the predictions of Moore's Law; i.e. the cost of mapping the entire genome of an individual has decreased faster than a logarithmic rate. A full genome analysis that would have cost roughly $10 million dollars on average in 2007, had fallen to a modest $8000 average by 2014; in a matter of several years, technology once reserved for the budgets of entire institutions had become a medical tool available to most patients ("DNA Sequencing Costs" 2014)[2]. In some instances the costs of whole genetic sequencing have fallen well-below $1000 and one company, 23andMe, has launched *partial* genome screening kits for ancestry and health for $99[3] (Gutierrez 2013; "Whole Genome Sequencing Rates" 2015).

Francis De Souza, president of biotech equipment manufacturer Illumina, Inc., posits that with current dropping costs in consumer genetic testing, the number of human genomes completely sequenced has reached approximately 228,000 as of 2014, and at the current rate of growth this number is projected to double over the next several years, purportedly "reaching 1.6 million genomes by 2017" (Regalado 2014).[4] This may represent a fraction of a percent of the world's population, but this number is significant enough that the ethical and legal debate of genetic information no longer hinges on whether or not this kind of information should be made available but rather, to whom it should be divulged.

Individuals now have a number of practical reasons to pursue genomic sequencing. Some patients and their spouses now use this information for "genetic counseling". This service

---

[2] See *Fig. 1 in Appendix.*

[3] The FDA has suspended 23andMe's health screening test in the United States, pending confirmation of its accuracy. This service is available however in Canada and the United Kingdom.

[4] *See Fig. 2 in Appendix.*

allows carriers of specific genetic traits to consult with medical professionals and interpret "family and medical histories to assess the chance of disease occurrence or recurrence" in themselves or their offspring (Uhlmann et al. 2009, 25). Others may one day soon be the first users of "gene therapy", a practice in which genetic material is "deliberate[ly] administrat[ed] into a human patient with the intent of correcting a specific genetic defect" ("Human Gene Therapy" 1984, 2). An entirely experimental concept throughout the 20th century, the first gene therapy treatment was approved for commercial use in Europe in 2012, and the FDA is currently pending approval of another such treatment here in the United States (Gallagher 2012; "FDA Grants Breakthrough..." 2014). With a growing number of consumer applications, genetic testing will gain widespread medical practice throughout the next decade, and with its implementation will come a host of regulations that will need to be consistent with social norms as well as legal precedent.

Genetic Information and Equality

Our understanding of human genetics is ever-advancing and their study holds potential for the treatment of diseases, prevention of heritable disorders, and even the prediction of certain social outcomes. However with the emergence of this new scientific frontier comes the concern that "[d]iscoveries [in human genetic science] will challenge the basic concepts of equality on which our society is based. Once we can say there are differences between people that are easily demonstrable at the genetic level, then society will have to come to grips with understanding [this newfound] diversity" (Baltimore 1983). Not unlike the initial discovery of trait heritability, human genetic information remains culturally tethered to an unfortunate heritage of eugenics and "racial hygiene"; as correlations are found between genes and certain health outcomes, societal values of "superiority" and equality may be tested.

The developed world has come a long way from the days of forced sterilizations, but the term "social engineering," and the attitudes associated with it, still persist in institutional circles. For example Dr. James Watson, the co-discoverer of DNA, was quoted as recently as 2003 saying, "If you are really stupid, I would call that a disease. The lower 10 per cent who really have difficulty, even in elementary school, what's the cause of it? A lot of people would like to say, 'Well, poverty, things like that.' It probably isn't. So I'd like to get rid of that, to help the lower 10 per cent" (Black 2003, 442).

This passage illustrates an enduring paradigm in which standards of intelligence and other social measures are espoused in the name of progress. It represents an interventionist attitude that proclaims one culture (those in the scientific community) must alter the nature of another (“the lower 10%”) for the betterment of humankind. One would be hard-pressed to disagree with the *aim* of Dr. Watson's statement, but its implications show a flagrant disregard for the tenets of human equality as well as our ever-changing understanding of humanity’s capacity to socially “measure” itself. The idea that an individual could be considered "diseased" by not meeting certain metrics is informed by social determinism– in classifying disorders, institutions apply systems of values they consider norms which said conditions exist in opposition to.

Social attitudes have, in the past, manifested in science in unfortunate ways, including the portrayal of homosexuality and minority traits as "undesirable" elements of "disease" in and of themselves. Aside from these extreme examples of "scientific racism", preconceived norms have managed to shape "scientific" paradigms in other less pronounced ways as ultimately "all disease classification is molded by socially created realities" (Bartlett 2005).

One striking example can be found in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (hereon abbreviated as "DSM"): entry 309.23 classifies adjustment disorder, *with work inhibition* as its chief symptom as an insurance-

recognized diagnosis. The official criteria for this diagnosis– effectively any noticeable reduction in the patient's capacity to complete work that was previous performed at some determined "optimal output" (Bartlett 2005, 29). Indeed the interpretation of the latter is something that could be considered from multiple philosophical vantage points, but the fact that work inhibition is considered a diagnosis for a medical disorder is an emphatic reflection of societal cultural values.

Watson's determinist views on stupidity as a "disease" conflict with the fact that across all cultures, ages, and other social strata there *exists no universally accepted measurement of intelligence* (Gardner 1983). Until recently low scores on intelligence quotient (IQ) tests were also listed in the DSM as a means of classifying individuals with "profound mental retardation," but one study at the University of Western Ontario found such tests, a Western mainstay in psychology, to be tone deaf as a single measure of cognitive ability. The authors conclude their paper by describing a series of pathway-systems in the human brain which they believe may be responsible for collective intelligence absent the biases of social status and poverty (Hampshire et al. 2012). One could argue the latter supports Dr. Watson's statement that "stupidity" is something that can be determined quantifiably in biology. However, given our limited understanding of epigenetics[5] and the fact that socially constructed measures of intelligence have high potential for obsolescence, this anecdote also illustrates how standards are all but static. Society's advanced scientific metrics of today may be considered rudimentary or even entirely false tomorrow. Attempts to base genetic "corrections," however humane their methodology may or may not be, on correlations with measurement systems that may not hold credibility in the future could, not only undermine equality, but the concept of objective scientific progress as well.

---

[5] The alteration of genetic expression over an individual's lifetime.

In this regard, eugenics and the attitudes their study was based upon, could be called the first institutionalized form of genetic discrimination. And though medical science and social attitudes towards race and sexuality have progressed, the idea of socially deterministic inequity remains.

Genetic Exceptionalism and the Roots of Discrimination

Few would argue explicitly *if* society should allow history to influence social enquiry, but rather the debate often centers around *how* such history should inform our future ethics and values. The emergence of genetic science has coincided with concerns that this information may have a unique ability to interact with social discrimination in ways not previously possible. A large part of these hypothesized practices hinges on what is known as "DNA exceptionalism" (Rowe 2015).

"DNA exceptionalism" is the idea that one's genetics can inform others of their future outcomes. One's genealogical makeup may reveal predispositions to certain negative health outcomes and as such is considered more sensitive than health information such as one's eye color, height, or past illnesses. With the exception of uniquely debilitating disorders (e.g. Downs Syndrome, the addition of an entire extra chromosome), cultural misconceptions exist that place DNA as a paramount prognosticator; code revealing the outcomes of individuals' incomes, health ailments, and lifespans.

Despite these beliefs, genetic counseling has limited credible uses and DNA isn't able to identify future behavioral patterns at this time, it isn't *necessarily* even a reliable predictor of several well-researched cancers. Indeed certain genes may show an association with tumor metastasis on a patient-by-patient basis, but rarely is a gene a tell-all of a person's future (Berns et al. 1998). Moreover, a recent study at Johns Hopkins Medical Institute found that for 23 of the

24 diseases their team studied, patients received negative results for "predictive" tests at rates far higher than the known rates of incidence for the diseases in question, indicating the tests yielded little useful insight in diagnosis (Roberts et al. 2012). Genetic research has consistently shown that monozygotic twins, even cloned animal specimens, can exhibit different phenotypes while having identical embryonic genotypes (Esteller 2008). Such research helped to open the field of epigenetics i.e. the processes both environmentally and within a living organism which influence genetic expression, causing profound genetic imprinting across multiple generations (Esteller 2008).

So if the study of codons can only inform us of relationships in a manner more like weather forecasts than clockwork, why would DNA be considered such sensitive information? With this context, attitudes towards human genetics and "genetic exceptionalism" itself may even sound farcical. At present nobody is going to be able to elicit the outcome of your health or social behavior in a way comparable to the “pre-crimes” of the Philip K. Dick's *Minority Report,* and there seems to be little indication that this is about to change. With that said, the study of genetics is not isolated from the narratives of "social pathology"; associations between certain genomic traits and groups, however anecdotal or scientifically unsound, may just as easily lead to the stigmatization of individuals with these characteristics– and in turn, *new identities subject to discrimination* (Tavani 2004). Correlations between certain disorders and risk factors will largely determine this.

The conception of discrimination is rarely directly tied to scientific inquiry, but rather preconceived social ideals. Institutional science strives to be objective, but while science can achieve objective truth mechanically/mathematically, the qualitative interpretation of quantifiable measurements is never aperspectival (Daston and Galison 2011). Rather the very standards by which objectivity is regarded are themselves subjective; as Hegel affirmed in his works on social

conscience, functionally speaking, subjectivity shapes the ethical life and norms of society (Brownlee 2011).

Assuming medical science were to completely unlock the correct interpretations of all 80,000 genes in the human body- there is little reason to believe that a business which makes its livelihood on the actuarial wellbeing of clients would not want to use said information to inform its conduct, even if clientele were to bear expenses inequitably as a result of this practice. Moreover a health insurance company doesn't need absolute proof of causation to model correlations for its coverage expenses, if there is some association between a certain order of codons and a negative health outcome– it is arguably in the business's best interest to prevent these losses. However by charging more (or otherwise rejecting) those who may present significant risk, this discrimination could be seen in some ways as an indirect form "negative eugenics". By providing substandard service to those individuals who are seen as dysgenic factors to a larger business model, insurers would in-effect create a deliberate and financially driven form of social determinism that would disadvantage particular groups of customers based on perceived returns.[6] Any practice where individuals are given disparate treatment based on the results of genetic testing is by definition "genetic discrimination". ("What is Genetic Discrimination?" 2015).

Contemporary Genetic Discrimination and Its Origins

Genetic discrimination first entered the American lexicon sometime in the early 1980s with the emergence of modern molecular biology ("'genetic discrimination' - Google Ngrams Search..."). One of the first scientists to address this in the public sphere was Dr. David

---

[6] It should be noted that the American insurance industry has not endorsed these practices, and rather in the United Kingdom the insurance industry has in fact placed a voluntary moratorium on the use of any genomic testing results. This is a discussion of a hypothetical practice, and is not meant to indicate that insurers are deliberately in favor of eugenic practices.

Baltimore, recipient of the 1975 Nobel Prize in Physiology and Medicine for his contributions in the genetics of cancer incidence. In a 1983 interview with U.S. New and World Report, Dr. Baltimore posed a question which summarized the problems of genetic discrimination-- "[with] a precise knowledge of heredity...are we going to see pressures [in American society] to channel people in specific directions because of genetic predispositions?" (Baltimore 1983).

Genetic discrimination law is unique in that, unlike most civil laws, its history has been more proactive than reactionary. There is a significant body of literature today that empirically shows some forms of discrimination in the lives and careers of at-risk populations, but up until the enactment of the 2008 Genetic Information Nondiscrimination Act (GINA), its conception largely stemmed from public attitudes towards genetic technology. While genetic discrimination has been documented, much of this record originally stemmed from perceptions rather than civil or criminal court cases. Early Congressional hearings on the subject were largely dedicated to polling, rather than case studies or court proceedings (Goh et al. 2013; Otlowski et al. 2012; "Congressional Hearings..." 2012). Because of this nebulous discourse, in the years up to the passage of the 2008 law there remained significant concern that legislators were "build[ing] bureaucracies around phantoms," rather than waiting to better understand what salient role genetics would play in society (Baltimore 1983). This concern passed altogether when the U.S. Equal Employment Opportunity Commission filed a discrimination case for "genetic bias" six years after the introduction of GINA's first draft (H.R. 2728 1995; "EEOC Settles..." 2001; "The Future of Genetic Nondiscrimination..." 2012). In this particular case the Burlington Northern Santa Fe Railway (BNSF) sought to commit employees filing for workman's compensation to blood tests for a gene associated with carpal tunnel syndrome ("EEOC Settles..." 2001). For many this first EEOC action was blatant confirmation of prior fears, and yet this was a case already covered by the language of the American Disabilities Act, as the outcome of this personal genetic test was for a specific disability that would have potentially impacted an

individual's employment. If a plaintiff had sued for being denied employment based on a gene *associated* with risks of cancer or a future heart condition, rather than a more specific disability, it remains dubious as to whether or not such a legal challenge would have held up in court at that time.

The Genetic Information Nondiscrimination Act (GINA)

Legislative History and Coverage

As genetic services began to affect more patients lives, Congress worked towards enacting legislation that would prevent discrimination in employment and insurance coverage based on an individual's genetic makeup. The process of getting this legislation passed was a decade-long endeavor, with more than 30 drafts brought before the House and Senate between 1995 and 2008 ("Congress.gov"). Both the initial and final drafts of the bill were introduced to the lower house by Congresswoman Louise Slaughter of New York, who advocated on behalf of the concerns of a number of social advocacy groups. Chief among these was the *Coalition for Genetic Fairness* in Washington, an advocacy alliance founded in 1997 by several non-governmental organizations including the National Partnership for Women & Families and National Society for Genetic Counselors (Terry 2011). By the time the Genetic Information Nondiscrimination Act (GINA) came to a final vote, the coalition's major contributing benefactors numbered in the hundreds, including several private businesses, medical colleges, disability advocates, and professional organizations (Terry 2011).

GINA was unanimously endorsed by the Senate on April 24, 2008, and met virtually no resistance in the House, passing by a margin of 414 to 1 ("Genetic Information Nondiscrimination Act" 2012). With its passage the Federal government had enacted "legislation establishing a national and uniform basic standard to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies." ("Full Text of the Genetic..." 2008).

Under Title II of the Genetic Information Nondiscrimination Act, employers, employment agencies, labor organizations, and training programs may not refuse to offer employment, admission, or membership, to an individual as a consequence of said individual's genetic

makeup. Additionally they may not deprive or categorize employees on these grounds should these designations "deprive [them] of employment opportunities" (*Ibid*). Rather than governing specific genetic testing practices, GINA significantly hinders potential for discrimination by restricting employers from "request[ing], requir[ing], or purchas[ing]" genetic information on the individual in question with certain strict exceptions.

These entities may request family medical histories– if they are in compliance with the *Family and Medical Leave Act of 1993*, if they are offering health or genetic services to the individual, if the genetic information is being used to monitor the biological effects of potentially harmful substances in an OSHA compliant worksite, or if genetic samples are being taken to maintain background quality control for law enforcement forensics. In all of these scenarios only medical professionals, genetic counselors, and other authorized personnel administrating these services may be granted access to this information on an individual basis; all genetic information furnished to employers must be stored in such a way that each person's files are individually unidentifiable. In the case of worksite genetic monitoring all individuals must be granted access to their own results of such tests and can only be committed to them if they have knowingly been informed of the test and volunteer to take part in it. Fortunately for employers the law exempts them from wrongdoing if an individual's genetics or family history is widely published in a public document such as a book, newspaper, magazine, or academic journal, *however* the law explicitly states that media such as medical databases and court proceedings do not fall under this exemption (*Ibid*).

Additionally Title I of the law specifically addresses insurance discrimination, rendering it illegal for health insurance providers to base premiums, group or individual, on the genetic information of a policy's members. GINA does not however mandate coverage for genetic testing– rather, individuals will need to prove its necessity to insurers on a case-by-case basis as with other medical services. Furthermore, the insurer reserves the right to increase premiums

in the event that a disease becomes manifested in a patient who otherwise previously showed a predisposition to said disease. The discrimination law applies to genotypic discrimination; phenotypical diseases, those which a patient has been diagnosed with, still fall under standard business practices for insurance providers.

GINA applies to virtually all Americans who work for employers or take part in labor groups and training programs of more than 15 employees, with a couple of additional exceptions: military personnel, veterans, and Federal employees all fall under their own respective systems of coverage. Fortunately for servicemen, the military and veterans administrations have recently issued protocol that enacts similar protections to GINA's own (Baruch & Hudson 2008). Federal employees have held such rights since 2000, when President Bill Clinton issued Executive Order 13145 to "prohibit discrimination in Federal employment based on genetic information...[applying] to every aspect of Federal employment" ("Executive Order 13145" 2000).

Outcomes

With this monumental piece of Federal legislation enacted, the question remains– is there any evidence that GINA has deterred genetically discriminatory practices over the last seven years, and are there any immediately apparent problems with the law as it stands today? Moreover, does the law's implementation raise any additional ethical questions about genetic disclosure practices?

It remains difficult to track the broad implications of GINA as there may not be widespread public awareness of the rights it grants to individuals (Prince 2015). The only major quantitative measure we have for its use comes from the EEOC's annual reports of charges filed against employers; last year 333 cases were filed against employers for genetic discrimination, comprising 0.4% of the tens of thousands of cases received in total ("Charge

Statistics FY 1997 Through FY 2014" 2015). Something equally telling is the ability for individuals to access literature that clearly explains GINA and its implications; when an employee sues an employer for genetic discrimination, the GINA's enforcement language stipulates that they must go through their state's EEOC counterpart to either settle the case or bring it to court ("Full Text of the Genetic..." 2008). As with most legal cases, the latter is typically a last resort; although EEOC statistics were published as early as 2010, the EEOC did not file and settle its first GINA-based lawsuit until 2013. In this unprecedented case a corporation, *Fabricut, Inc.*, made the mistake of mandating a job applicant's family medical history, details that GINA covers as a form of protected genetic information (Wagner 2013).

The law is also vague as to how the Federal government would handle such a case in the event that a state was either not honoring their own GINA-related laws or lacked such laws; this could become a matter of administrative penalties, or a case brought before Federal District Courts (Prince 2015). This contingency is highly unlikely however, as it appears all states have at least imposed laws meeting the most stringent requirements of GINA.

Unfortunately, at this time there is no authoritative source on the individual laws of all 50 states. The National Conference of State Legislatures previously maintained a list of all state laws barring genetic discrimination, but this information has not been updated since GINA was signed into law, and its completeness up until that time is somewhat questionable ("Genetic Privacy Laws" 2008). For example, the table lists North Dakota as having no prior state protections for genetic discriminatory practices and yet there is legislation predating GINA, as well as health insurance literature, which indicate that this kind of information could not be used as a "pre-existing condition" prior to the passage of the 2008 law ("Chapter 26.1-36.4" 1995; Pollitz et al. 2004). Moreover while Pennsylvania and Tennessee have both furnished post-GINA laws that explicitly state their coverage of this statute, Mississippi's Code proved impossible to find through the expected online channels (Ch. 89, Sec. 791 PA 2009; Chapter 0780-01-58 TN

2010). Presently the Mississippi Legislature only discloses a 1972 version of its Code in one online database, but statutes which include GINA protection are not among these laws nor legislative bills of the last decade. As it turns out Mississippi ultimately pursued GINA provisions through a different legal avenue– regulations. The Mississippi Department of Insurance proposed new regulations to the secretary of state which were implemented in 2009 (Gachaneau 2009). GINA is expressly disclosed in discrimination policies by Mississippi public institutions however this state appears to lack a readily-accessible database which cites their legal language ("Policies Regarding Discrimination..." 2014; "The Emergency Food Assistance Program" 2014). The National Human Genome Research Institute does maintain a Genome Statute and Legislative Database however, as of writing, this resource yields zero entries for the State of Mississippi ("The Genome Statute and Legislation Database" 2014). Knowledge of these laws empowers the citizens they are meant to protect, as such the aforementioned inconsistencies demonstrate some evidence of a gap in the literature meant to better inform citizens about GINA and its state counterparts.

The Genetic Information Nondiscrimination Act is limited in scope as well; although it does consider a number of employment and employment-related organizations in its protections, its insurance coverage does not extend to life, disability or longterm care insurances, services provided to consumers that could be significantly impacted by genetic outcomes. While Congress hasn't explicitly stated its reasoning for not including such coverage in the bill, this was likely done to keep the law politically feasible; there was likely little desire to prolong its approval following more than a decade of unratified drafts (Prince 2015; "The Future of Genetic Nondiscrimination..." 2012). One must also consider that disability and longterm care insurance will generally have smaller pools of applicants than health insurance plans, and may be more likely to regard genetic discrimination laws as a hinderance to their business practices (Prince 2015).

While there is some talk of expanding GINA coverage at the Federal level, states are welcome to expand their discrimination laws, regardless of Congressional inaction, as long as their laws meet the standards outlined in GINA. Massachusetts is one of these states, with additional protections explicitly provided in its own respective genetic discrimination legislation. As of 2015, 19 states have outlawed genetic discrimination practices in longterm care insurance, as well as 18 for disability insurance, and 14 with statutes preventing the use of genetic information in premium-setting for life insurance (*Ibid*). The latter has been approached in a number of ways, with some states allowing the gathering of genetic information for underwriting life insurance policies with an individual's consent, while others have granted life insurers the right to appeal their use of genetic information on actuarial grounds (*Ibid*). Two states, Vermont and New York, have gone a step further and passed laws allowing *no* insurer of *any kind* to use genetic information to set premiums (*Ibid*).

California's expansion of the Federal statute is perhaps the most comprehensive state law. CalGINA, ratified in 2011, offers additional protections from the collection of genetic information for housing and mortgage practices, as well as penal, electoral, and social services. The law is extremely wide-reaching as it amends the 1959 Unruh Civil Rights Act to include protections from genetic discrimination in the conduct of "all business establishments of every kind whatsoever" (Zimring & Bashaw 2001). Additionally CalGINA removes Federal limitations on the damages a single genetic discrimination case can be filed for ("Full Text of the Genetic..." 2008; "The California Genetic Information..." 2012). Some may indeed argue that this kind of legal language is excessive and could bring about a disproportional number of cases relative to the actual incidence of demonstrable genetic discrimination. A quick review of EEOC California statistics quickly dispels this notion however; genetic discrimination cases represented an average 0.4 percent of EEOC cases in California since CalGINA's passage, with California representing on average 8% of all national cases of GINA filings in that same time. When one

considers that California, the most populous state in the Union, comprises about 12% of the nation's citizens, it seems entirely reasonable for CalGINA to represent less than that portion of all national EEOC/GINA filings ("FY 2009 - 2014 EEOC Charge Receipts by State" 2014; "California; State & County Quickfacts" 2015). Since this law has only been in place for a few years, future analyses will need to be conducted to determine if this outcome is typical and not an artifact of its brief history.

Limitations

Arguably the most contentious aspect of genetic laws remains in the disclosure of genetic information. Unlike one's phenotypic traits such as eye color, weight, or the number of times an individual has come down with influenza, genomics hold the potential to reveal information not only about a single individual, but several generations of their relatives as well. In addition to the privacies provided in GINA, genetic information also falls under the protections of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which prevents the release of identifiable information by medical professionals (Gutmann 2012). Ironically, as people have become more concerned about the privacy of their genetic information, contemporary medical researchers have made use of increasingly larger data sets to inform their genomic research, presenting an ethical juxtaposition of legal protections, and the ideal conditions needed for scientific progress.

Genetic information is sensitive by virtue of its own medium; there are simply no large stacks of paper lying around with the billions of codons transcribed from each genetic test. As affirmed in one 2004 abstract on information and communications technology (ICT) and genetics, in simple terms "there [are] no new genetics without computer science" (Marturano and Chadwick 2004). The law can protect individual's information symbolically, but the collective nature of genotypes renders this difficult to accomplish, particularly if one’s relatives have made

their own data available to the public. Although this may not be a common circumstance, this scenario holds the potential to undermine the basic principles of laws like HIPAA and GINA. A research group at MIT was recently able to link identified genetic information with that of anonymous relatives by using repeated codon patterns on male member Y chromosomes and online genealogical databases (Gyrmek et al. 2013). Across a number of iterative searches their team was able to identify otherwise anonymous DNA contributed for research purposes with a success rate of 18%, and concluded that with additional data this method could be made significantly more accurate (Gyrmek et al. 2013). At present time this means that at least 1 in 5 individuals whose files are anonymously on record can be found using the information from just a handful of identified genomes or, in other words, a few hundred identifiable male genomes have the potential to reveal those of several thousand previously anonymous individuals. It's too early to say to what extent this risk may grow, but in light of these findings, clearer encryption policies for ICT data and control-access databases may need to be explored in order to ensure A) that these findings won't deter volunteers from contributing to genetic medical projects, and B) that their information can't be used to undermine the privacy of others. With growing interest in bioinformatics, large genetic databases may be key to translating codon patterns into phenotypical traits, but until regulatory or technological solutions come into place, individuals must be informed of the potential risks of disclosing their genes both for their own benefit and that of the research teams responsible for its storage (McDonnell 2015).

Historically the United States has always been associated with a culture that places the individual before the collective. These attitudes are emblematic in our hesitance to adopt social programs, or perhaps our aversion to policies of redistribution; they are equally resonant with the value placed on privacy. While one's genetic information is their own however, it is also their parent's, their children's, their family's. Not legally, but biologically-speaking, an individual's

heritable risk factors for certain diseases and disorders are not solely theirs, but rather can serve as potential warnings for their relatives.

This leaves an ethical question largely ignored by GINA and the discussions that surrounded its framing. Should relatives of an individual who is genetically tested have some right to know if that test yields an outcome that could adversely affect them? There may be a certain abstract value we place on genetic privacy tied to our conception of dignity, but at what point do tangible health benefits outweigh this value? Namely, should doctors be allowed to openly inform persons affected by a genetic carrier gene that might lead to a debilitating or fatal condition in themselves or their offspring? At this time similar statutes exist in some states for specific medical contexts; several have "duty to warn" laws for HIV/AIDS diagnoses and severe psychiatric disorders where the patient is considered a potential threat to others ("Connecticut..." 2014, 32; "Michigan HIV Laws..." 2006, 8; "Mental Health Professionals'..." 2013). Some statutes mandate that doctors inform those affected by these afflictions, others leave it up to their discretion.

In other contexts where such statutes don't exist, there has been some discussion by medical professionals over the use "libertarian paternalism," popularized by Harvard economist Cass Sunstein as "nudge theory" (Sunstein & Thaler 2003; Cohen 2013). The basic concept behind this theory is that professionals may use positive reinforcement and suggestion to induce what they perceive to be the most beneficial decision for the individual and others affected by said individual's choices (Sunstein & Thaler 2003). Proponents argue that such practices help to steer patients in the most "welfare-promoting direction" without removing their freedom of choice (*Ibid*). Although there has been some acceptance of this approach by the Federal government and medical communities alike, it relies far more on internal regulations and professional training than codified policy. This method is especially useful in cases where there is significantly disparate information between the patient and the doctor. If a medical doctor is not

obligated to report a health outcome and does not have the contact information of those they wish to inform, such tactics might induce the patient to relay this information to those who would be affected by it.

Current HIPAA law does however allow for doctors to inform relatives through one indirect channel. The language in HIPAA's privacy rule contains a proviso in which medical information, ergo genetic information, may be relayed if it will be used in the treatment of another individual ("Under the HIPAA Privacy Rule" 2009). Ultimately this means that if one doctor has contact with the doctor of another family member or significant other, they can relay the results of genetic testing to the other physician who then has the discretion to potentially inform their patient if they believe in their professional opinion that this individual could benefit from this knowledge ("Under the HIPAA Privacy Rule" 2009; Prince 2015). In this way HIPAA does have a function which allows important genetic outcomes to reach those who may be affected by them, but this law is reliant on a couple of factors. Firstly, it assumes that the doctor of the patient receiving the test believes that the results are important enough to disclose and that said doctor can readily contact the doctor of the patient's significant other. Barring family groups with the same health provider, there may be instances where a such contact information may not be readily available. Secondly, it assumes that the other doctor in this chain of communication will believe that its disclosure to their patient is the best course of action. Although both may be informed professionals, a difference of opinion is not unheard of, and may or may not be in the best interest of those whom this information impacts. While this law does allow for the transmission of this information without the patient's overt consent, it also grants the patient the right to request its confidentiality and "[does] not require an explanation from [said patient] as to the basis for [this] request" ("Under the HIPAA Privacy Rule" 2009; 45 CFR 164.522). For this reason this proviso is somewhat of a catch-22, in that its mechanism for relaying this information functions, at least in part, on the ignorance of the patient who had

received the genetic test. If a patient wishes to disclose this information to others, it is theirs to divulge, however if the patient does not, the only way that a physician can relay this information is if the patient does not know the details of HIPAA's privacy clause to begin with. This law may have a function for disclosing medically important information, but it would be difficult to call the current system ideal. (*See Appendix I for further explanation.)*

Policy Recommendations

Rather than simply making this genetic information solely the property of individuals, even in extenuating circumstances, or placing it in the ethically grey area of the HIPAA privacy law, I propose that these laws be updated to better reflect the collective nature of genetic information. France, for example, has created a unique provision by which doctors may report genetic test results if these results should indicate the patient is a carrier of a fatal disorder or one that, if expressed, could greatly hinder the independence of their offspring. Should this be the case, physicians must inform the next of kin and anyone, relatives or spouses, who may be affected by this condition. The law explicitly states that if these individuals are deceased or otherwise unreachable, doctors may contact those who are up to 5 generations removed from the patient to inform them that they too may be carriers of these genes. The law does not give doctors the authority to mandate that their patients get tested, there is no provision for mandatory genetic counseling, nor will this information be disclosed to employers or insurers. Rather such a law provides affected populations with more complete information that empowers them to alter their lifestyles and consult family planning professionals. Due to the nature of American law, and the value it places on precedence, such a statute would likely represent a political firestorm, however, given the collective nature of genetics, and the "duty to report" precedents set by HIV/AIDs laws and the handling of psychological disorders, this is a concept that might warrant merit in the American legal system ("Arrête Du 8 Décembre..." 2014).

In much the same way as Congress had hearings over GINA in its initial drafting, it should also hold such hearings over expansion of the law for disability, longterm care, and life insurance. The latter has proven to be a contentious issue in state regulations, and unless some form of standards are set which inform this conduct, these practices will remain ethically ambiguous and may result in disparate consumer rights across state lines. Similarly consumer services offering partial genome testing like 23andMe may need to be addressed by Congress

and other legislative bodies (in the interim) to further define acceptable scenarios for employers, insurers, and other entities in which the outcomes of these tests are "inadvertently" obtained on the internet. One problem with GINA and its counterparts stems from the fact that their disclosure protections solely rely on the *intent* of employers to "request, require, or purchase" genetic information ("Full Text of the Genetic..." 2008). Without further refinement of legal language, modern social media holds the potential to undermine GINA's protections (Ragouissis et al. 2014). There is presently no Federal statute rendering it illegal for an employer to request access to their employees' social media accounts and any posts or messages associated with them. If an individual were to find out from a testing service that they were a carrier for genes which show a strong affinity for Alzheimers', they might feel compelled to message this information to potentially affected relatives. If an employer were to come upon this message without explicitly stating an intent to find this kind of information, there would be little room for legal recourse, and as intrusive as this practice may seem, there are currently only 11 states which have made it illegal for employers to ask for social media passwords (Dame 2014). There are two ways this scenario may be prevented with Federal legislation– firstly, social media could be amended to those "publicly available" resources which are not exempt from employer acquisition, currently listed in paragraph 4, subsection b of sections 202-205 of GINA respectively ("Full Text of the Genetic..." 2008). Secondly, Federal legislation could be passed which explicitly prevents supervisors from requiring access to an employer's social media as a condition of employment. It remains illegal under the Computer Fraud and Abuse Act of 1986 for an employer (or anyone for that matter) to access someone's computer accounts without their permission, but for some employees the thought of losing their job is simply not an option, allowing such workplace coercion to continue (18 U.S. Code § 1030). Until the Federal government or the remaining 39 state legislatures take action on this matter, the most practical remedy for this situation remains in education- by informing individuals that this situation could

arise in states where employer social media access is legal, they may choose other (legally protected) mediums to inform their relatives and partners of their genetic test results.

Its clear from the existing literature, that no matter how GINA and its related policies are expanded, patients will need something the law cannot give them on its own-- education. However many times the Congress or state legislatures attempt to rectify the above criticisms in *any* manner, their measures will only be as effective if citizens know their rights. Additionally the medical community and lawmakers must address "[if] widespread clinical application of WGS, [whole genome sequencing], is medically and ethically appropriate" (Rothstein 2012). One thing lost on this debate is that GINA, for all of the ways it could be expanded, already offers an extremely broad definition of genetic information. Any amount of code, any documented family tree, is covered under this law. At this time it is possible for individuals to get genetic testing and genetic counseling services that do not make use of whole genome sequencing; for all of the perceived concerns that exist about the disclosure of genetic information, it's still up to the consumer to put it out there. The attitudes of the American people toward this technology were what shaped GINA and its contemporaries, this does not mean the law has to necessarily redefine these attitudes. People need to know the risks and benefits of the many genetic services currently available to them; rather consumers could benefit from being able to find all of this information in a single user-friendly resource. The Presidential Commission for the Study of Bioethical Issues and the National Human Genome Research Institute both serve their purposes and both provide information readily available for professionals, the Equal Employment Opportunity Commission provides useful information for those who need to know what GINA considers genetic information but for those who just want to know more about their risks and family histories, the full picture isn't offered in one convenient resource. The least that can be done is for the Congress Research Service or one of its Federal counterparts to determine what areas of the this broader system of protective law that Americans do and don't

understand. From there, we will begin to gain a better picture of the realities of genetic discrimination, and how we can move forward to support citizens' contributions to medical research concurrently with reasonable privacy protections.

Conclusion

Though the Genetic Information Discrimination Act of 2008 (GINA) represents a forward-thinking statute, it's apparent from existing legal and scientific literature that this law will face numerous challenges in its future implementation. Despite the best efforts of legislators to endow patients with greater protections, these mechanisms will only be effective as long as they are widely known. To further empower patients, educational resources must be made available to them so they may better understand the inherent privacy risks that come with divulging their genetic information, both for themselves and their relatives.

GINA and its counterpart, the Health Insurance Portability and Accountability Act of 1996 (HIPAA), may address individual protections, but given the similarities of one's own DNA to those related to them, it makes sense both from an ethical and practical perspective to re-evaluate current treatment disclosure policies. In some circumstances it may prove beneficial to allow doctors to inform other patients of their relatives' tests, regardless of the patient's willingness to disclose this information, if said tests reveal carrier genes of potentially debilitating or fatal outcomes.

As human genomes are sequenced in greater numbers over the next decade, it is the author's hope that this report will inform policymakers of the ethical and legal histories that have shaped GINA, especially in its limitations where science and law have yet to reach a practical resolution that addresses the inherently collective properties of genetic information. For science to be conducive to the greatest societal benefit it must be rooted in ethics of equality, for laws to most benefit society they must remain based on the latest understandings of science. To best protect all individuals from disparate treatment, professionals from both fields must continue facilitate a productive dialogue in the years ahead.

Bibliography

18 U.S. Code § 1030 - "Fraud and Related Activity in Connection with Computers." U.S. Code; Legal Information Institute at Cornell University Law School. Accessed April 2, 2015. https://www.law.cornell.edu/uscode/text/18/1030.

45 CFR 164.522 - "Rights to Request Privacy Protection for Protected Health Information." Code of Federal Regulations; Legal Information Institute at Cornell University Law School. August 14, 2002. Accessed April 2, 2015. https://www.law.cornell.edu/cfr/text/45/164.522.

"Arrêté Du 8 Décembre 2014 Définissant Les Règles De Bonnes Pratiques Relatives à La Mise En œuvre De L'information De La Parentèle Dans Le Cadre D'un Examen Des Caractéristiques Génétiques à Finalité Médicale." Legifrance, Le Service Public De La Diffusion Du Droit. December 19, 2014. Accessed April 4, 2015. http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000029921462&categorieLien=id.

Baltimore, David. "Can Genetic Science Backfire? 'That's the Chance We Take'; A Conversation with David Baltimore." Edited by Alvin P Sanoff. U.S. News and World Report, March 28, 1983.

Barlett, Steven James. The Pathology of Man a Study of Human Evil. Springfield, IL: Charles C Thomas Publisher, 2005.

Baruch, Susannah, and Kathy Hudson. "Civilian and Military Genetics: Nondiscrimination Policy in a Post-GINA World." The American Journal of Human Genetics 83, no. 4 (2008): 435-44.

Berns, E. M., I. L. Van Staveren, M. P. Look, M. Smid, J. G. Klijn, and J. A. Foekens. "Mutations in Residues of TP53 That Directly Contact DNA Predict Poor Outcome in Human Primary Breast Cancer." British Journal of Cancer 77, no. 7 (1998): 1130-136. Accessed March 31, 2015. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2150115/.

Black, Edwin. *War Against the Weak: Eugenics and America's Campaign to Create a Master Race*. New York: Four Walls Eight Windows, 2003.

Brownlee, Timothy. "Conscience and Religion in Hegel's Later Political Philosophy." Edited by Ardis B. Collins. *Owl of Minerva* 43, no. 1 (2011): 41-73.

"California; State & County QuickFacts." U.S. Census Bureau. March 31, 2015. Accessed April 2, 2015. http://quickfacts.census.gov/qfd/states/06000.html.

"Chapter 0780-01-58; Medicare Supplement Insurance Minimum Standards." In Rules of Tennessee Department of Commerce and Insurance. Nashville: Tennessee Division of Insurance, 2010.

"CHAPTER 26.1-36.4 Hospital and Medical Insurance." In Century Code of North Dakota, 1. Bismarck: State of North Dakota, 1995.

"Ch. 89, Sec. 791: Prohibition against Use of Genetic Information and Requests for Genetic Testing." In The Pennsylvania Code. Harrisburg: Commonwealth of Pennsylvania, 2009.

"Charge Statistics FY 1997 Through FY 2014." U.S. Equal Employment Opportunity Commission. January 1, 2015. Accessed April 5, 2015. http://eeoc.gov/eeoc/statistics/enforcement/charges.cfm.

Cohen, Shlomo. "Nudging and Informed Consent." The American Journal of Bioethics 13, no. 6 (2013): 3-11.

Congress.gov. Accessed April 2, 2015. https://www.congress.gov/search?q={"source":"legislation","search":"genetic nondiscrimination","type":"bills"}

"Congressional Hearings and Testimony on Genetic Discrimination in Health Insurance and Employment." National Human Genome Research Institute. March 7, 2012. Accessed April 2, 2015. http://www.genome.gov/11510232.

Connecticut: Overview of Legal Issues for People with HIV. GLAD, LGBT Legal Advocates, 2014. 32.

Dame, Jonathan. "Will Employers Still Ask for Facebook Passwords in 2014?" USA TODAY, January 10, 2014. Accessed April 2, 2015. http://www.usatoday.com/story/money/business/2014/01/10/facebook-passwords-employers/4327739/.

Daston, Lorraine, and Peter Galison. "The Image of Objectivity." Representations 40, no. 3 (1992): 81-128.

"DNA Sequencing Costs." National Human Genome Research Institute. October 31, 2014. Accessed March 31, 2015. http://www.genome.gov/sequencingcosts/.

"EEOC Settles ADA Suit Against BNSF for Genetic Bias." U.S. Equal Employment Opportunity Commission. April 18, 2001. Accessed April 2, 2015. http://www.eeoc.gov/eeoc/newsroom/release/4-18-01.cfm.

Esteller, M. "Epigenetics In Cancer." New England Journal of Medicine 358 (2008): 1148-159.

"Executive Order 13145 to Prohibit Discrimination in Federal Employment Based on Genetic Information." National Human Genome Research Institute. February 8, 2000. Accessed April 2, 2015. http://www.genome.gov/10002084.

"FDA Grants Breakthrough Status to Gene Therapy for First Time." Bio-IT World, April 10, 2014.

"Full Text of the Genetic Information Nondiscrimination Act of 2008." U.S. Equal Employment Opportunity Commission. May 21, 2008. Accessed April 3, 2015. http://www.eeoc.gov/laws/statutes/gina.cfm.

"FY 2009 - 2014 EEOC Charge Receipts by State (includes U.S. Territories) and Basis." U.S. Equal Employment Opportunity Commission. January 1, 2015. Accessed April 2, 2015. http://www1.eeoc.gov/eeoc/statistics/enforcement/charges_by_state.cfm.

Ganucheau, Stephanie L. Notice of Proposed Rule Adoption; Amendment to Reg. 96-103. Jackson: State of Mississippi, 2009.

Gallagher, James. "Gene Therapy: Glybera Approved by European Commission." *BBC News*, November 2, 2012, Health sec.

Gallo, Agatha M., Denise B. Angst, and Kathleen A. Knafl. "Disclosure of Genetic Information Within Families." AJN, American Journal of Nursing 109, no. 4 (2009): 65-69.

Gardner, Howard. Frames of Mind: The Theory of Multiple Intelligences. New York: Basic Books, 1983.

"'genetic Discrimination' - Google Ngrams Search Results." Google Ngram Viewer. Accessed March 2, 2015. https://books.google.com/ngrams/graph?content="genetic discrimination"&year_start=1980&year_end=2000&corpus=15&smoothing=3&share=&direct_url=t1

"Genetic Information Nondiscrimination Act (GINA) of 2008." National Human Genome Research Institute. March 16, 2012. Accessed April 3, 2015. http://www.genome.gov/24519851.

"Genetic Privacy Laws." National Conference of State Legislatures. January 1, 2008. Accessed April 2, 2015. http://www.ncsl.org/research/health/genetic-privacy-laws.aspx.

Goh, Anita M.y., Edmond Chiu, Olga Yastrubetskaya, Cheryl Erwin, Janet K. Williams, Andrew R. Juhl, and Jane S. Paulsen, And The I-Respond-Hd Inves. "Perception, Experience, and Response to Genetic Discrimination in Huntington's Disease: The Australian Results of the International RESPOND-HD Study." Genetic Testing and Molecular Biomarkers 17, no. 2 (2013): 115-21.

Gutierrez, Alberto. "Warning Letter: 23andMe, Inc." U.S. Food and Drug Administration. November 22, 2013. Accessed March 31, 2015. http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/2013/ucm376296.htm.

Gutmann, Amy, ed. Privacy and Progress in Whole Genome Sequencing. Washington: Presidential Commission for the Study of Bioethical Issues, 2012.

Gymrek, M., A. L. Mcguire, D. Golan, E. Halperin, and Y. Erlich. "Identifying Personal Genomes by Surname Inference." *Science*, 2013, 321-24.

Hampshire, Adam, Roger R. Highfield, Beth L. Parkin, and Adrian M. Owen. "Fractionating Human Intelligence." Neuron 76, no. 6 (2012): 1225-237. Accessed March 30, 2015.

Human Gene Therapy- A Background Paper. Vol. 32. Washington, D.C.: Congress of the United States, Office of Technology Assessment :, 1984.

Lee, Sandra Soo-Jin, and Emily Borgelt. "Protecting Posted Genes: Social Networking and the Limits of GINA." *The American Journal of Bioethics* 14, no. 11 (2014): 32-44. Accessed April 2, 2015.

Lynn, Richard. "13. Negative Eugenics: Incentives, Coercion, and Compulsion." In Eugenics, a Reassessment. Westport, Conn.: Praeger, 2001.

Marturano, Antonio, and Ruth Chadwick. "How the Role of Computing Is Driving New Genetics' Public Policy." *Ethics and Information Technology*, 2004, 43-53.

McDonnell, Tim. "For Preventing Disease, Data Are the New Drugs." Nautilus. February 5, 2015. Accessed February 13, 2015. http://nautil.us/issue/21/information/for-preventing-disease-data-are-the-new-drugs-rp.

"Mental Health Professionals' Duty to Warn." National Conference of State Legislatures. January 1, 2013. Accessed April 2, 2015. http://www.ncsl.org/research/health/mental-health-professionals-duty-to-warn.aspx.

Michigan HIV Laws: How They Affect Physicians and Other Health Care Providers. Michigan Department of Community Health, 2006. 8.

Otlowski, M., S. Taylor, and Y. Bombard. "Genetic Discrimination: International Perspectives." Annual Review of Genomics and Human Genetics 13 (2012): 433-54.

"Policies Regarding Discrimination on the Basis of Sexual Orientation." The University of Southern Mississippi, Gulf Coast. March 1, 2014. Accessed April 3, 2015. http://www.usm.edu/gulfcoast/alliance-equality/policies-regarding-discrimination-basis-sexual-orientation.

Pollitz, Karen, Eliza Bangit, Kevin Lucia, Jennifer Libster, Jennifer Hersh, and Mila Kofman. A Consumer's Guide to Getting and Keeping Health Insurance in North Dakota. Washington, D.C.: Georgetown University Health Policy Institute, 2004.

Prince, Anya. "Conversation with Post-doctoral Fellow Anya Prince of UNC-Chapel Hill's Center for Genomics & Society." Telephone interview by author. March 10, 2015.

Ragoussis, V., IN Feze, and Y. Joly. "Sharing Genetic Information Online: An Exploration of GINA's 2.0 Frontier." The American Journal of Bioethics 14, no. 11 (2014). Accessed April 2, 2015.

Regalado, Antonio. "EmTech: Illumina Says 228,000 Human Genomes Will Be Sequenced This Year." MIT Technology Review, September 24, 2014.

Roberts, N. J., J. T. Vogelstein, G. Parmigiani, K. W. Kinzler, B. Vogelstein, and V. E. Velculescu. "The Predictive Capacity of Personal Genome Sequencing." Science Translational Medicine, 2012, 133ra58.

Rothstein, Mark A. “The Genome Sequencing and Privacy Report: A Missed Opportunity” *GeneWatch*. Oct-Nov. 2012

Rowe, Chip. "Your DNA Is Nothing Special." Nautilus, February 5, 2015. Accessed March 31, 2015. http://nautil.us/issue/21/information/your-dna-is-nothing-special

Sunstein, Cass R, and Richard H Thaler. "Libertarian Paternalism Is Not an Oxymoron." The University of Chicago Law Review 70, no. 4 (2003): 1159-202.

Tavani, Herman T. "Genomic Research and Data-Mining Technology: Implications for Personal Privacy and Informed Consent." Ethics and Information Technology, 2004, 15-28.

Terry, Sharon. "About the Coalition for Genetic Fairness." Coalition for Genetic Fairness. January 1, 2011. Accessed April 3, 2015. http://www.geneticfairness.org/about.html.
"The California Genetic Information Nondiscrimination Act (CalGINA) Q and A." The California Genetic Privacy Network. January 1, 2012. Accessed April 2, 2015. http://geneticprivacynetwork.org/about-calgina/.

"The Emergency Food Assistance Program (TEFAP)." Mississippi Department of Human Services. March 1, 2014. Accessed April 3, 2015. http://www.mdhs.ms.gov/the-emergency-food-assistance-program-(tefap)/.

"The Future of Genetic Nondiscrimination Legislation; An Interview with Congresswoman Louise Slaughter." GeneWatch, January 1, 2012, 18.

"The Genome Statute and Legislation Database." National Human Genome Research Institute. June 12, 2014. Accessed April 2, 2015. https://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm.

"The Human Genome Project Completion: Frequently Asked Questions." National Human Genome Research Institute. October 30, 2010. Accessed March 31, 2015. https://www.genome.gov/11006943.

Uhlmann, Wendy R., Jane L Schuette, Beverly Yashar, and Ann P Walker. "The Practice of Genetic Counseling." In A Guide to Genetic Counseling. Hoboken, NJ: John Wiley & Sons, 2009.

"Under the HIPAA Privacy Rule." Office for Civil Rights, U.S. Department of Health and Human Services. January 13, 2009. Accessed April 2, 2015. http://www.hhs.gov/ocr/privacy/hipaa/faq/right_to_request_a_restriction/512.html.

Wade, Nicholas. "In the Genome Race, the Sequel Is Personal." The New York Times, September 4, 2007. Accessed March 31, 2015. http://www.nytimes.com/2007/09/04/science/04vent.html.

Wagner, Jennifer K. "EEOC Files and Settles Its First GINA-based Employment Discrimination Lawsuit on May 7, 2013." Genomics Law Report, May 13, 2013. Accessed May 13, 2013. http://www.genomicslawreport.com/index.php/2013/05/13/eeoc-files-and-settles-its-first-gina-based-employment-discrimination-lawsuit-on-may-7-2013/.

"What Is Genetic Discrimination?" Genetics Home Reference; U.S. National Library of Medicine. March 30, 2015. Accessed April 2, 2015. http://ghr.nlm.nih.gov/handbook/testing/discrimination.

"Whole Genome Sequencing Rates." Science Exchange. April 2, 2015. Accessed April 2, 2015. https://www.scienceexchange.com/services/whole-genome-seq.

Zimring, Stuart D., and Donna R. Bashaw. "Footnotes." In California Guide to Tax, Estate & Financial Planning for the Elderly. New York, NY: LEXIS Pub., 2001.

Appendix

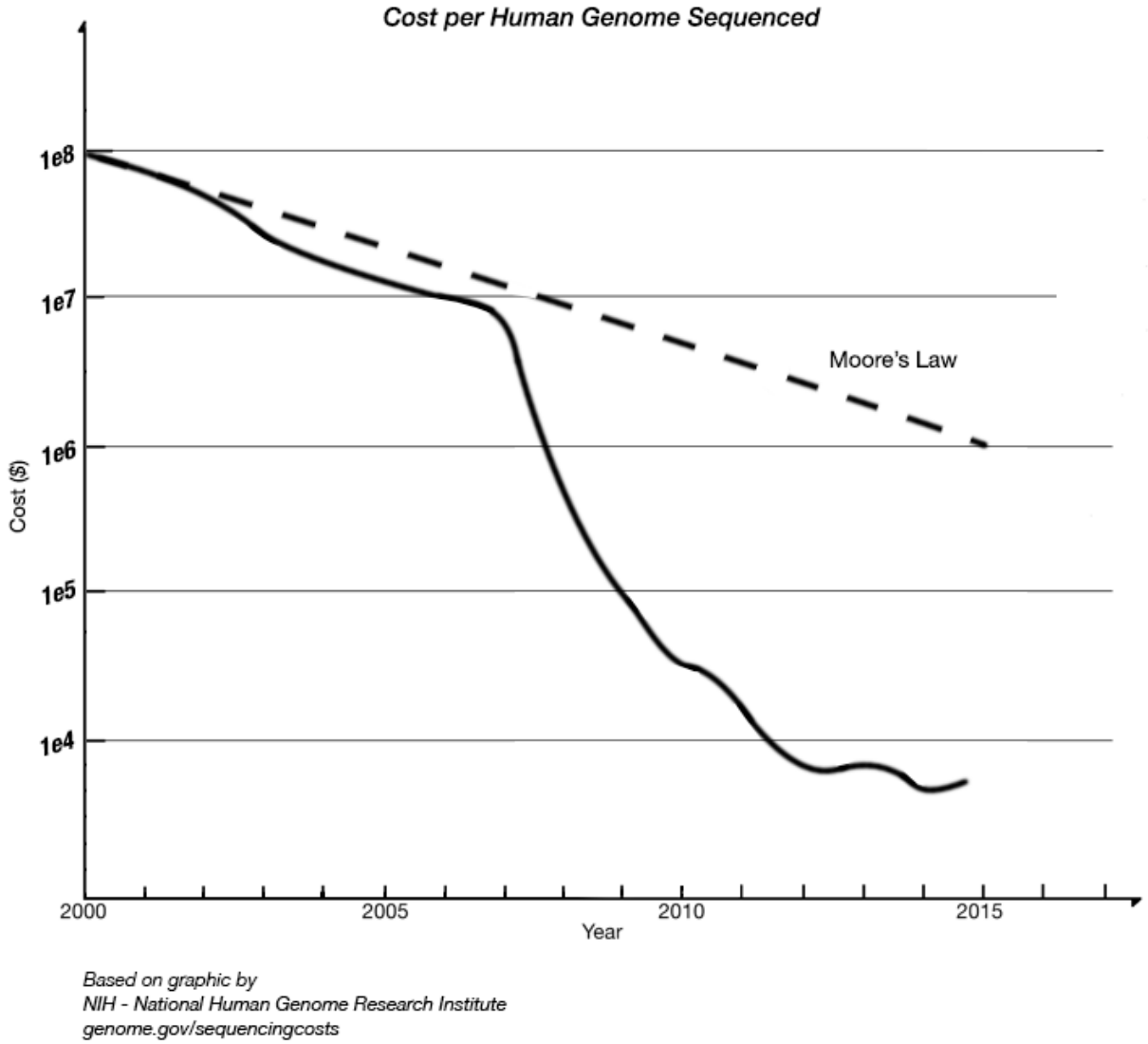
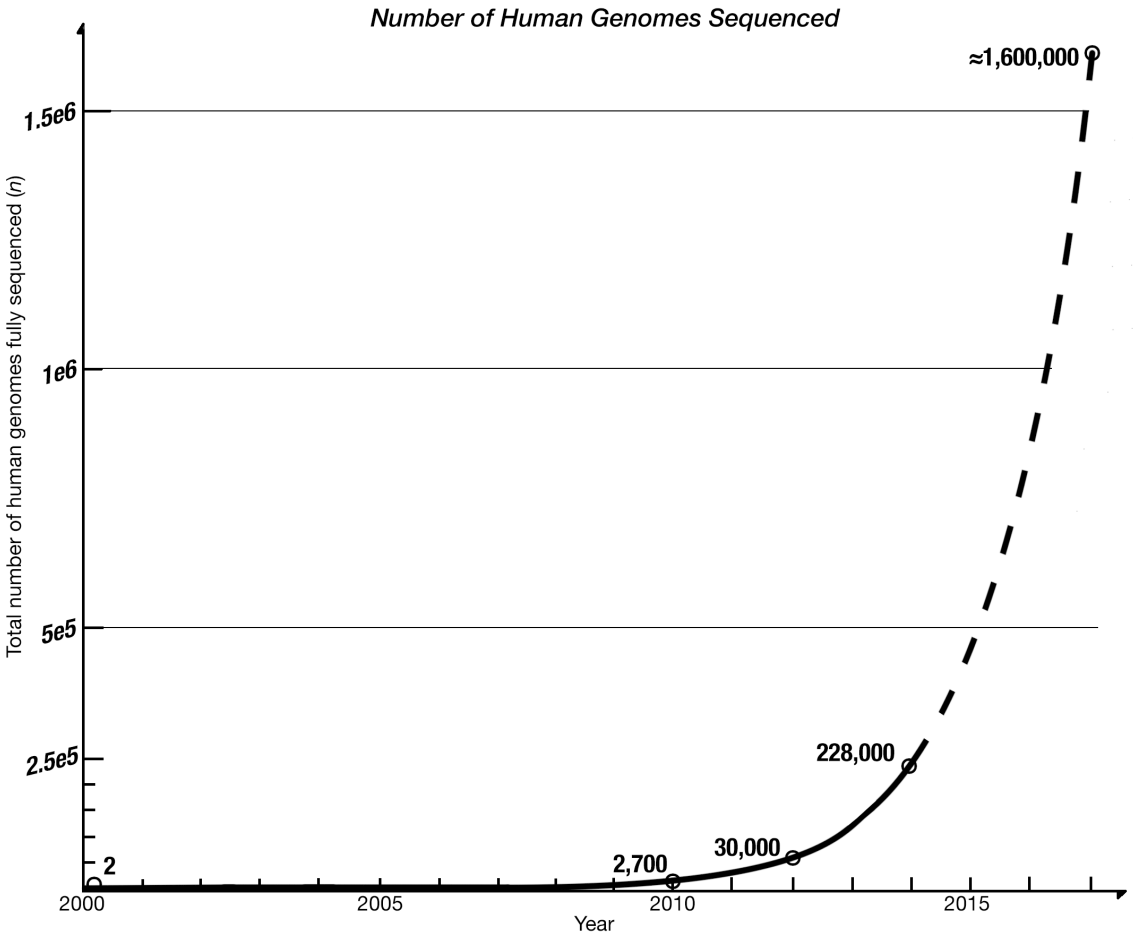


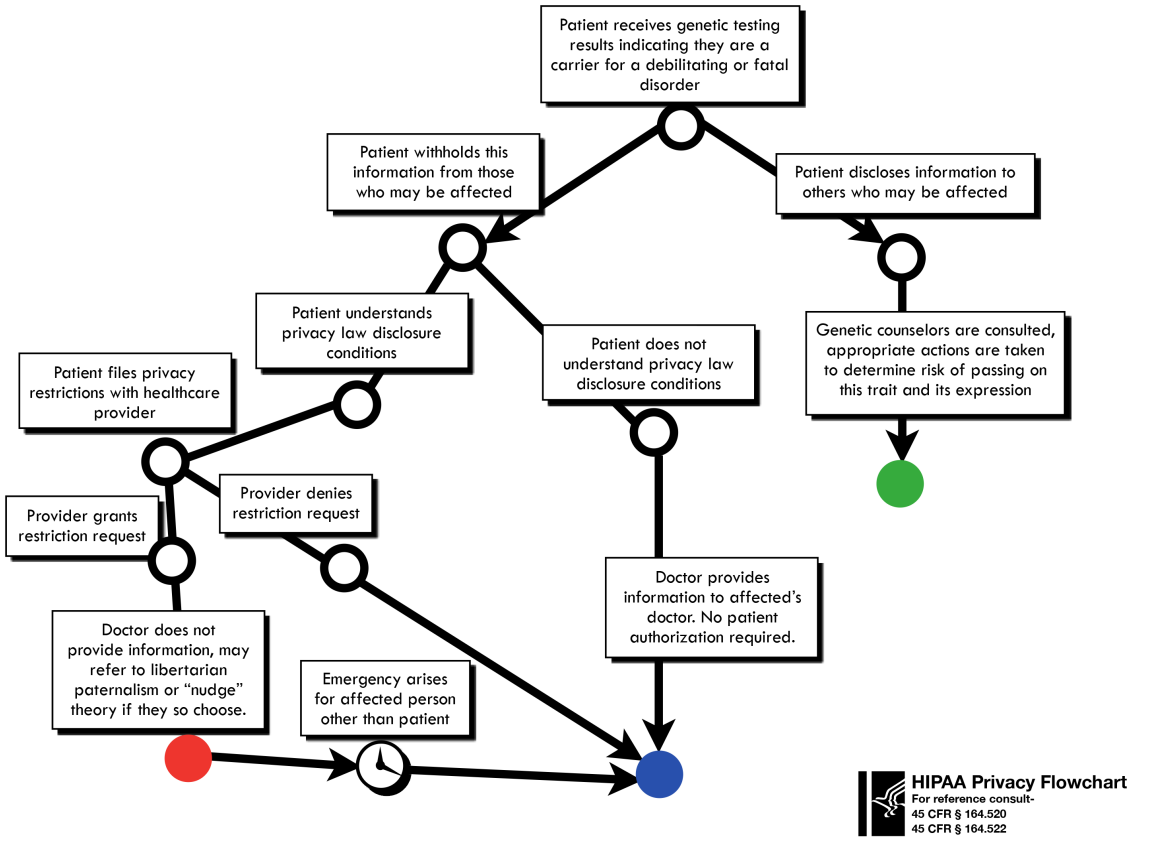
Fig. 1



Sources: "Genomes by the Thousand." *Nature* 467 (2010): 1026-027. Accessed April 20, 2015. http://www.nature.com/news/2010/101027/pdf/4671026a.pdf

Regalado, Antonio. "EmTech: Illumina Says 228,000 Human Genomes Will Be Sequenced This Year." *MIT Technology Review,* September 24, 2014.

Fig. 2



Outcome in which patient refuses to disclose genetic test results, doctor restricted from disclosure

Outcome in which patient refuses to disclose genetic test results, doctor still discloses information to affected parties

Outcome in which patient willingly discloses genetic test results to those affected

Fig. 3